

## 'UNLIKE ANY OTHER' White House PMI Summit Outlines 'Bold Initiative'

President Obama's Precision Medicine Initiative (PMI), first unveiled at his January 2015 State of the Union address, took another major step forward on Feb. 25 at the White House PMI Summit. Held in the White House's south court auditorium and webcast live, the event included the announcement of initial steps based on recommendations offered just 5 months ago by a PMI working group.

"This will be a bold initiative unlike any other," said NIH director Dr. Francis Collins, adding that, in his 25 years at NIH,

no initiative has ever been faster to take shape. "We're all different...the one-size-fits-all approach [to health care] is far from optimal." PMI will take into account the contributions of genes, environment and lifestyle in an "unprecedented effort," he said.

Collins said it would take 3-4 years to assemble a study cohort of more than 1 million individuals, who scientists hope to follow for years. The effort is not focused on any specific disease, he said, nor is PMI "just about illness—it's also about health." Important clues to disease prevention are expected to emerge from the data.

Three factors distinguish PMI from other large-cohort studies of the past, Collins said. Participants will be "true partners," not patients; the cohort will be broadly representative of the nation's population; and data-sharing is to be swift to both participants and scientists.

SEE **PMI SUMMIT**, PAGE 4



President Barack Obama participates in PMI summit panel Feb. 25 at the White House.



Peace Corps alumni now work at NIH; see p. 3.

### ALSO THIS ISSUE

Briefs .....	2
Peace Corps Work Unites Cadre of NIH'ers .....	3
Seydel To Give NIAID Neva Lecture .....	5
Digest .....	9
Milestones .....	10
Volunteers .....	11
Seen .....	12

## THE DIGITAL DOCTOR Health Care IT May Need a Reboot, Wachter Says

BY DANA TALESNIK

In today's high-tech world, doctors increasingly have their heads buried in their computers. While they're feverishly typing in patient data, digitally prescribing medicines and reviewing electronic health records, personal relationships are deteriorating. Digitized health care has left many doctors and their patients literally not seeing eye to eye.

Dr. Robert Wachter, chief of the division



Dr. Robert Wachter

SEE **WACHTER**, PAGE 8

## NEI Program for People with Disabilities Marks 10 Years

BY DANIEL STIMSON

Andrew Butler may be one of the hardest working people at NIH. He has to be, because he works at the Bldg. 49 Central Animal Facility on campus—home to the many rodents and other laboratory animals that are a vital part of NIH research. Butler's daily shift in the cage wash and facility support area starts at 7 a.m. each day, but he arrives promptly at 6:15. Even after Winter Storm Jonas tore through the East Coast on Jan. 22 and snarled the NIH area for most of the following week, he reported to work on time every day except for that Monday, when his supervisors advised that he stay home.

Butler happens to be one of several workers with intellectual disabilities at the Bldg. 49 facility, which serves labs at several institutes and centers and is

SEE **ANNIVERSARY**, PAGE 6

## Workshop on Preventing Youth Suicide, Mar. 29-30

NIH will convene a Pathways to Prevention Workshop: Advancing Research to Prevent Youth Suicide on Mar. 29-30 in Masur Auditorium, Bldg. 10. A panel will identify research gaps and future research priorities.

Suicide was the second leading cause of death for youth (10- to 24-year-olds) in 2014, resulting in 5,504 deaths in the United States. This mortality has not decreased compared to other external causes of death; youth suicide attempts have remained at consistent rates for decades.

The Office of Disease Prevention, NIMH, NIDA and NCCIH are sponsoring the workshop. Sign language interpreters will be provided. Those who need reasonable accommodation to participate should contact Deborah Langer via email at [langerdh@od.nih.gov](mailto:langerdh@od.nih.gov).

For more information and to register for the workshop, which is free and open to the public, visit <https://prevention.nih.gov/programs-events/pathways-to-prevention/workshops/suicide-prevention>.

## Volunteer for Science, Engineering Festival, Apr. 16-17

NIH will have its own pavilion at the widely attended USA Science & Engineering Festival (USASEF) held at the Walter E. Washington Convention Center, Apr. 16-17.

The festival is the nation's largest celebration of science, technology, engineering and math (STEM). The free biennial event is open to children of all ages and their family and friends. The 2014 event attracted more than 325,000 people to its many hands-on activities, enticing visitors young and old to learn, create and explore the wonders—and excitement—of STEM. USASEF is open 10 a.m.-6 p.m. Saturday, Apr. 16 and 10 a.m.-4 p.m. Sunday, Apr. 17.

If you are an NIH staff member, you are also invited to volunteer at the NIH Pavilion, a vast anchor exhibit in the Health and Medicine Pavilion featuring activities organized by 19 institutes, centers and offices. This is a great opportunity for NIH employees to communicate their enthusiasm for science and technology to the public. For information on volunteering, visit <https://dpcpsi.nih.gov/SciFest>.

## Management Intern Program Recruits

The NIH Management Intern Program, a way to unlock a new career path, is recruiting Apr. 4-8. It is a highly competitive, 2-year career-development program for current NIH employees. MIs come from a variety of job backgrounds including both scientific and administrative fields. Upon completion of the program, MIs transition into an administrative-management career in one of many areas throughout NIH. Eligible employees



## NIAMS Holds Career Development Forum

NIAMS recently hosted its fourth annual career development forum for extramural researchers who are in the third year of a mentored clinical scientist development (K08) or patient-oriented research (K23) grant. In addition to the K awardees, the forum included physician-scientists who recently received R01 (or equivalent) awards, established researchers and representatives of professional and voluntary organizations. The group discussed challenges junior investigators face when pursuing research independence. K awardees also had an opportunity to present their research and to interact with NIAMS leadership and program, review and grants management staff, including director Dr. Stephen Katz; deputy director Dr. Robert Carter; Dr. Susana Serrate-Sztejn, director of the Division of Skin and Rheumatic Diseases; Dr. Joan McGowan, director of the Division of Musculoskeletal Diseases; Dr. Marie Mancini, director of the Systemic Autoimmunity Program, Division of Skin and Rheumatic Diseases; and Dr. Amanda Boyce, director of the Muscle Development and Physiology Program, Division of Musculoskeletal Diseases.

PHOTO: RICH CLARK

are invited to apply. For program FAQs and details about eligibility, visit <http://trainingcenter.nih.gov/intern/mi/>.

Learn more by attending any of these information sessions, all of which are held from noon to 1 p.m.:

- Mar. 22, Bldg. 31, 6C, Rm. 6
- Mar. 23, Bldg. 45, NIH Training Center (adjacent to cafeteria)
- Mar. 28, Rockledge 1, Suite 4000, RT1

## Down Syndrome Registry Expands to Spanish Population

Down syndrome (DS) is one of the most common genetic causes of developmental and intellectual disabilities in the United States. According to the Centers for Disease Control and Prevention, approximately 6,000 babies are born in the U.S. each year with Down syndrome, or about 1 out of every 691 live births.

Little is known about the global health impact of DS, such as heart defects, gastrointestinal malformations and other medical and behavioral issues. Further research is needed to develop the next generation of novel therapies and compounds aimed at improving cognition, reducing dementia and mitigating other manifestations of DS.

To help address this need, the National Institute of Child Health and Human Development created a web-based, voluntary registry called DS-Connect (<https://dsconnect.nih.gov>) in 2013; it collects

demographic and health information about individuals with DS. It will provide information to doctors and scientists about how DS affects those suffering from the disease and foster new educational, behavioral and pharmaceutical treatments.

Drs. Melissa Parisi and Sujata Bardhan of NICHD's Intellectual and Developmental Disabilities Branch were instrumental in developing DS-Connect. They explain that while people with DS are living longer, researchers and health care providers do not know what issues are related to typical aging in this population. DS-Connect provides a portal to consolidate health information across the lifespan.

"There are currently more than 3,200 people with Down syndrome who have joined the registry and we want to see that number grow," said Parisi.

The researchers recognized the need to expand outreach efforts to include Spanish-speaking people, so last June, DS-Connect en Español was launched.

Parisi and Bardhan also work with the Down Syndrome Consortium to obtain feedback and help promote both the English and Spanish DS registries. Through research, they say, scientists can gain a better understanding of Down syndrome and develop early interventions to improve the quality of life for children and adults with this disorder. **R**



## Peace Corps Service Unites Cadre of NIH'ers

When Ebola struck West Africa recently, Dr. Peter Kilmarx responded. He led the CDC Ebola response team in Sierra Leone for a month in 2014 and assisted another in Guinea for a month in 2015. Kilmarx, an infectious disease researcher, credits his 2-year Peace Corps service in the Democratic Republic of the Congo (then Zaire) for enabling the success of these trips and his career in public health.

As current deputy director of Fogarty International Center, he is one of dozens of returned Peace Corps volunteers (RPCV) who work at NIH. The group of returned volunteers started meeting regularly last fall and has 29 people on its listserv. However, Ella Ewart-Pierce, one of the group's coordinators, says that number is growing. Members meet regularly for lunch and plan to participate in local volunteer projects. The group's goal is to network and support NIH staff members who have Peace Corps in their backgrounds and potentially attract more returned volunteers to federal service. Members who served in 24 countries currently work across more than 10 NIH institutes, offices and centers.

For Kilmarx, 2 years as a fisheries volunteer in Africa in the mid-1980s was the start of his career in public health. He was the first Westerner in the small village of Bakwa-Tombe. Kilmarx spent those years building tilapia fish ponds alongside 20 farmers and their families. Everyone lived in thatched or mud huts without electricity or running water. "I'm still in touch with them, and they continue to raise fish," Kilmarx says.

It was the measles deaths in his village that got him interested in infectious diseases. Kilmarx wondered how the deaths were still possible. He had been vaccinated for measles prior to joining the Peace Corps. When he returned to the U.S. in 1986, he enrolled in medical school.

Carol Sienché, a health educator at the National Cancer Institute, also served in Africa in the 1980s. She was a school health educator in the Central African Republic from 1986 to 1988. Like Kilmarx, she lived in the middle of the community in a small house without running water or electricity. She traveled up to 120 kilometers by motorcycle to teach health lessons to local elementary school teachers.

However, it was the cultural hurdles she overcame that shaped her experience. "It's not enough to articulately deliver information, we must understand our audience's contextual and cultural realities if we hope to reach and help them," Sienché says. She earned her master's degree in public health from Tulane University and now develops educational content for people with cancer, their families and health care professionals.

Claire Schuster, a health specialist with the National Institute of Allergy and Infectious Diseases, served



Dr. Peter Kilmarx (r), returned Peace Corps volunteer (Zaire, 1984-1986), visits home of headman in quarantined village in Port Loko, Sierra Leone, while serving as team leader, CDC Ebola response, October 2014.



Carol Sienché (r), returned Peace Corps volunteer (Central African Republic, 1986-1988), purchases jewelry in Dakar, Senegal, circa 1988.



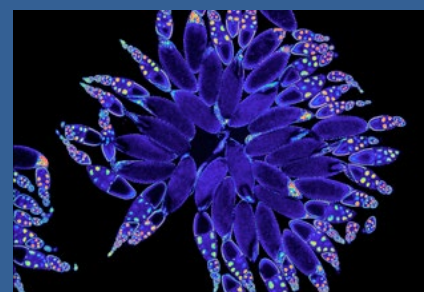
Claire Schuster (r), returned Peace Corps volunteer (Paraguay, 1997-1999), works with Dr. Ann Berghout Austin (Utah State University) on a child development project in Paraguari, Paraguay, circa 1999.

about a decade after Kilmarx and Sienché. She was a rural health educator in Paraguay from 1997 to 1999. While there, she learned Spanish and Guarani, an indigenous Paraguayan language. Her work focused on improving maternal and child health in her community of about 100 families.

Schuster's health lessons included nutrition, dental hygiene and adolescent health. She also helped with vaccination campaigns. She says the Peace Corps tested her understanding of public health challenges and energized her to engage communities to develop sustainable solutions to those challenges. After returning home, she earned her master's in public health and joined NIAID's International Maternal Pediatric Adolescent AIDS Clinical Trials Network (IMPAACT).

"Working with IMPAACT felt like an extension of my Peace Corps service because I had the opportunity to interact with communities all over the world and help bring their voices to the clinical research process," she says.

Returned volunteers are encouraged to join the NIH RPCV group by sending an email to [RPCVS\\_AT\\_NIH@list.nih.gov](mailto:RPCVS_AT_NIH@list.nih.gov) with only the following text in the message body (no signature): subscribe RPCVS\_AT\_NIH your name. **R**



ON THE COVER: A fruit fly ovary contains as many as 20 eggs.

IMAGE: HOGAN TANG & DENISE MONTELL

### The NIH Record

Since 1949, the *NIH Record* has been published biweekly by the Editorial Operations Branch, Office of Communications and Public Liaison, National Institutes of Health, Department of Health and Human Services. For editorial policies, email editor or phone (301) 496-2125.

**Editor:** Rich McManus  
[Rich.McManus@nih.gov](mailto:Rich.McManus@nih.gov)

**Associate Editor:** Carla Garnett  
[Carla.Garnett@nih.gov](mailto:Carla.Garnett@nih.gov)

**Staff Writers:**  
Eric Bock • [Eric.Bock@nih.gov](mailto:Eric.Bock@nih.gov)  
Dana Talesnik • [Dana.Talesnik@nih.gov](mailto:Dana.Talesnik@nih.gov)

Subscribe via email: [listserv@list.nih.gov](mailto:listserv@list.nih.gov) Follow: <http://nihrecord.nih.gov/>



The *NIH Record* is recyclable as office white paper.

**NIH** National Institutes of Health  
*Turning Discovery Into Health*

## PMI Summit

CONTINUED FROM PAGE 1

Collins said a central institutional review board has been established and that both a coordinating center and biobank, to accept tissue specimens, will be in place by this summer.

“It will truly take a coalition of partners,” said Collins, noting that the White House event drew at least 40 partners from academia, industry and the nonprofit sector. “[PMI] has the potential to transform medicine and health.”

“This is an incredibly exciting time in medicine generally, and the biological sciences,” said Obama, who participated in one of the event’s panels. “A lot of this traces back to work that was done mapping out the human genome.”

The President said that PMI “offers the promise to reduce costs, provide much better care [and] make our entire health care system much more effective...We may be able to accelerate the process of discovering cures in ways that we’ve never seen before.”

Obama said he hopes we can look back in 10 years “and say we’ve revolutionized medicine.”

On a panel with the President was Dr. W. Marston Linehan, chief of NCI’s Urologic Oncology Branch. He described the tortuous process of searching for a single-gene cause of kidney cancer in the era preceding the Human Genome Project. “We now know that it’s a number of different types of cancer that just happen to occur in that organ,” he said.

Not only that, but there are at least 16 genes involved in the development of kidney cancer, with more to be identified, Linehan said.

The rationale for PMI could be traced in his recitation of two kidney cancer cases. It took 18 years for Linehan and his colleagues to find out what kind of cancer killed a patient they first saw in 1989. But in a kidney cancer patient he had seen just the day before the summit, Linehan said no obvious evidence of cancer could be found on the



On the panel at the Feb. 25 White House Precision Medicine Summit are (from l) Dr. James Hamblin, senior editor at *The Atlantic* and panel moderator; President Obama; Sonia Vallabh, Harvard Medical School Ph.D. student and researcher at the Broad Institute of MIT; Howard Look, president, CEO and founder of Tidepool; Dr. W. Marston Linehan, chief of NCI’s Urologic Oncology Branch. Obama noted, “Our Precision Medicine Initiative has been designed to get all these various building blocks brought together so that the whole is greater than the sum of its parts.”

IMAGES: WHITE HOUSE

★ ★ ★

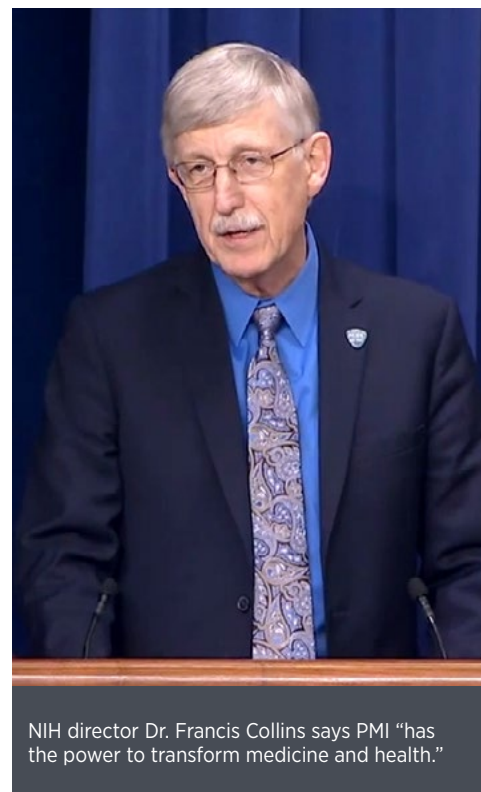
*“This will be a bold initiative unlike any other...We’re all different...the one-size-fits-all approach [to health care] is far from optimal.”*

—DR. FRANCIS COLLINS


★ ★ ★

x-ray of this person who was treated with a more appropriate drug—tailored to her disease—than could ever have been imagined for the initial patient.

“I’m not saying we don’t have miles to go before we sleep,” said Linehan, “but we are very encouraged by the progress that has been made. We know that we have a lot of work to do...We couldn’t practice medicine without what we now call precision medicine. We really couldn’t do it. It helps us decide whether to recommend an operation or not; what operation to recommend; what drugs to give. Our most important long-term goal is prevention. It is incalculable to us what this has meant to us and how it directs how we manage these patients.”



NIH director Dr. Francis Collins says PMI “has the power to transform medicine and health.”

To learn more about PMI, visit [www.nih.gov/precision-medicine-initiative-cohort-program](http://www.nih.gov/precision-medicine-initiative-cohort-program). —Rich McManus 



## Malaria Researcher Will Present NIAID Neva Lecture, Mar. 24

NIAID will hold the Franklin A. Neva Memorial Lecture on Thursday, Mar. 24, at 11 a.m. in Lipsett Amphitheater, Bldg. 10. Dr. Karl Seydel will present “Dissecting the Pathophysiology of Cerebral Malaria.”

Seydel is interested in the clinical heterogeneity of malarial disease. While some children with malaria have life-threatening symptoms



with a relatively low level of parasites in their blood, others have no symptoms but a large number of parasites in their blood. He has recently identified levels of a parasite protein, pHRP2, to be an accurate marker for those children who will progress from mild disease to life-threatening severe disease. He has also recently found that massive brain swelling is a powerful predictor of death in children with cerebral malaria.

Seydel splits his time between clinical and research duties in Blantyre, Malawi, where he has been overseeing the establishment of a Molecular and Genomics Laboratory.

Seydel is assistant professor in the College of Osteopathic Medicine at Michigan State University and director of the Molecular and Genomics Laboratory at the University of Malawi College of Medicine in Blantyre. He earned medical and doctoral degrees in 1999 from Washington University in St. Louis, where he participated in its Medical Scientist Training Program.

Seydel joined the faculty of Michigan State University's department of osteopathic specialties after working for 6 years as a fellow at NIAID's Laboratory of Malaria and Vector Research. He holds M.S. and B.S. degrees in biological sciences from Stanford University.

The lecture series honors Neva, a noted virologist, parasitologist and clinician and former chief of NIAID's Laboratory of Parasitic Diseases. He died in 2011.

## ADVISORS

### Three Join NLM Board of Regents

The National Library of Medicine board of regents welcomed three new members at its recent meeting. The new members are:

Dr. Alessandro Acquisti, professor of information systems and public policy at Carnegie Mellon University's Heinz College and member of Carnegie Mellon CyLab. His research focuses on the economics of privacy.

Dr. Daniel Masys, affiliate professor of biomedical and health informatics at the University of Washington School of Medicine. He previously chaired the department of biomedical informatics at Vanderbilt University School of Medicine.

Dr. Jill Taylor, director of the Wadsworth Center, New York State department of health. Taylor, whose background is in public health research, is responsible for the day-to-day functioning of the Biggs Laboratory in Albany, N.Y.



NLM Acting Director Betsy Humphreys (third from l) welcomes new board of regents members (from l) Dr. Alessandro Acquisti, Dr. Daniel Masys and Dr. Jill Taylor.

### NIAMS Council Welcomes Four

Four new members were recently named to the National Arthritis and Musculoskeletal and Skin Diseases Advisory Council.

Magdalena Castro-Lewis is former vice president for programs at the National Alliance for Hispanic Health in Washington, D.C. She has extensive experience with developing culturally and linguistically appropriate health education materials and forming national and community-based partnerships to improve the health of Hispanic families.

Dr. Ethan Lerner is an associate professor of dermatology at Harvard Medical School and an associate biologist in dermatology at Massachusetts General Hospital's Cutaneous Biology Research Center. His research is keyed to the mechanisms that underlie the itch sensation in order to develop effective anti-itch therapies.

William Mulvihill is a special advisor to the president of the University of Cincinnati and executive director of the University of Cincinnati Presidential Bicentennial Commission. He currently serves as trustee emeritus of the Arthritis Foundation and is on the board of directors for the Alliance for Lupus Research in New York.

Dr. Stephen Tapscott is a member of the divisions of human biology and clinical research at Fred Hutchinson Cancer Research Center in Seattle. His research focuses on gene expression in certain cancers and muscular dystrophies as well as gene and cell therapies for muscular dystrophy.



NIAMS director Dr. Stephen Katz (third from r) and deputy director Dr. Robert Carter (third from l) welcome new members to the institute's council. They are (from l) Dr. Stephen Tapscott, Magdalena Castro-Lewis, William Mulvihill and Dr. Ethan Lerner.

PHOTO: ERNIE BRANSON



**Above:** Andrew Butler works in the cage wash area. At right, Butler (second from r) is surrounded by (from l) job coach Vicky Geiger, supervisor Hugues Tagne-Mkam and Butler's parents Cathy and Charlie Butler.



## Anniversary

CONTINUED FROM PAGE 1

managed by NEI's veterinary research and resources section.

Butler, who has autism, graduated from Seneca Valley High School in Germantown, Md., in 2006 at age 21. The high school helped connect Butler to job training and to his job coach Vicky Geiger of Rehabilitation Opportunities, Inc. When Butler graduated, she found him a volunteer mailroom position at Shady Grove Medical Center and later helped bring him to NIH and the Bldg. 49 facility. She is still working with Butler and his parents 8 years later.

Butler is quiet and not one to sing his own praises, but Geiger says he is "very proficient" in his work. His parents, Charles and Cathy Butler, describe him as happy and an inspiration to his friends.

The NEI-led animal facility established a program for employing people with intellectual and developmental disabilities (IDD)

10 years ago and now employs 5 people with IDD including Butler. In December 2015, the facility's management team published an article about the program in *Laboratory Animal Science Professional*, the magazine of the American Association for Laboratory Animal Science.

Their goal? "We want to get the word out that people with IDD continue to be an underutilized resource who can markedly improve your workforce," said Dr. Robert Weichbrod, chief of animal program administration at NEI. He is senior author of the paper, along with Dr. James Raber, animal program director for NEI and NIMH.

### Skilled and Dedicated

In their article, the authors point out that animal care and use programs face many staffing challenges. Entry-level jobs at these facilities tend to offer low pay. These jobs can also be physically demanding and stressful, with the potential for daily operations to grind to a halt if someone is absent

or not keeping up with work flow. Employees also face several occupational risks, such as potential injuries from heavy machinery, animal bites and scratches and possible allergic reactions to fur, dander and animal waste. There are many procedures to ensure employee safety—and animal welfare—that

need to be followed precisely.

Meanwhile, people with IDD are often overlooked as potential employees. An analysis by the White House Council of Economic Advisors found that only one-third of working-age Americans with disabilities were employed from 2010-2012, compared to more than two-thirds of Americans without disabilities during the same period.

• • •

*"Our support for each other goes beyond the workplace. There is a dedication from management and families that makes the program very close-knit."*

-ALEXINE CHEVALIER

• • •

Weichbrod and his co-authors say that the key to changing that statistic is to look past a person's disabilities to his or her unique skills, attitudes and life experiences. Their team members with IDD "have a remarkable commitment to the job that is rarely seen in the workforce," Weichbrod said. "They come in early, or when they're not feeling well, or when there's inclement weather. They are extremely proud of the work they do."

During Winter Storm Jonas, Katherine Hall spent 3 nights in Bldg. 49 sleeping on a cot. Hall, who has Asperger syndrome, is a licensed veterinary technician at the facility



From l, Joe Wu, Dr. Robert Weichbrod, Owen White and Daniel Owusu



and has worked there since May 2015. (She is also a member of the board of directors for the Autism Society of Northern Virginia.) She takes care of the facility's mice and rats, which includes feeding them, changing cages and doing health checks to report illnesses, births or other issues.

Prior to joining the animal facility staff, Hall worked for a veterinary hospital in Alexandria. The hospital was "a small space with a lot of chaos going on all the time," she said. "Here, it's more working with animals than working with customer service. I've always loved animals and I kind of understand them better than people. I really enjoy it here."

### Dream Job

The NEI program began thanks to a chance encounter at a Special Olympics event. Weichbrod, whose late daughter Gretchen was a Special Olympics athlete, has been an ardent participant in the organization's events and fundraisers. In December 2005, he was at a Special Olympics holiday party when an Olympian named Joe Wu struck up a conversation with him and asked about job opportunities.

As it happened, the NEI facility had a need for additional staff. So Wu was brought in as a volunteer to work on the loading dock. After a trial period, he became a paid contractor and advanced to other facility support positions.

"It's been my dream job," Wu said.

Wu's experience became a model for taking on other staff with IDD, with community resource providers helping fulfill recruitment. These are organizations that receive state and local funds to support employment for people with disabilities, in part through job coaches like Geiger. The coaches know the abilities of the candidate and learn about the needs of the workplace; they help to manage expectations, performance and satisfaction on both sides. There are regular check-ins involving family members, the job coach, management and human resources, including an annual review required by Maryland law.

### Challenges and Solutions

What advice do Weichbrod and his colleagues offer for other workplaces interested in recruiting people with IDD? One step is to get involved with community groups such as Special Olympics and Best Buddies, which can help employers make connections, advertise job opportunities and share success stories.

The authors also advise seeking help from non-profit organizations that aim to improve employment for people with disabilities. For example, the organization Seeking Equality, Empowerment and Community for People with Developmental Disabilities and the Ivymount School in Rockville have partnered to sponsor and manage



Katherine Hall examines one of the mice in her care.

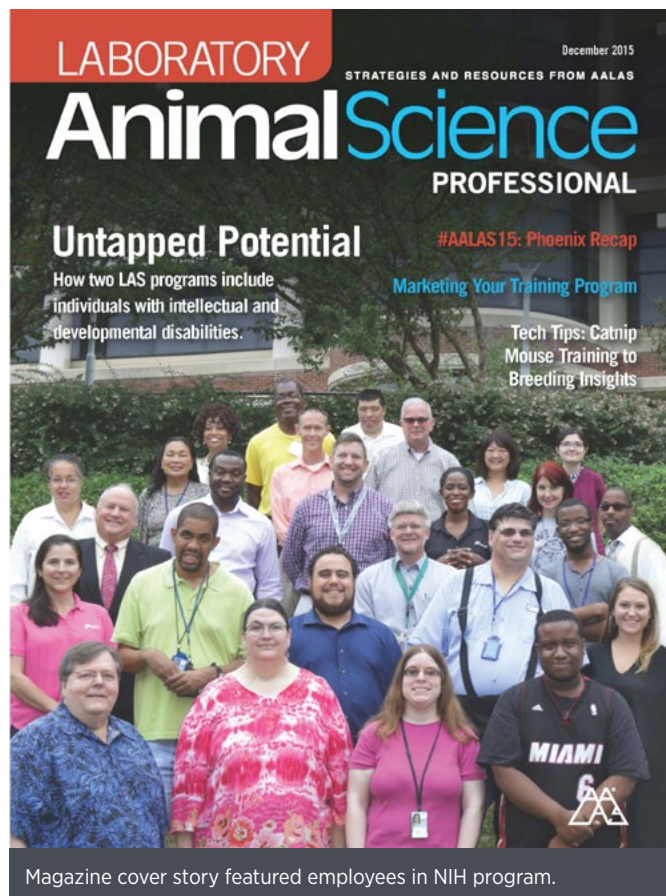
PHOTOS: BILL BRANSON

a 1-year internship program at NIH. It's called Project SEARCH and is designed for young adults with IDD who are high school seniors or recent graduates. While most of the interns work at the Clinical Center, some have worked in NIH's animal care and use programs, including the Bldg. 49 facility.

For federal employers, the Department of Labor has an online toolkit that offers training and best practices for recruiting and retaining people with disabilities. It followed a 2010 Executive Order by President Obama directing the federal government to become a model employer of workers with disabilities.

The NEI program's managers are candid about the many challenges of employing people with IDD, including the time and resources that must be invested for special training. They say these costs are balanced by lower employee turnover and recruitment costs. They also advise allowing more time for people with IDD to adapt if there is a need to change job responsibilities. People with IDD may also have more difficulty adjusting to new staff and saying goodbye to coworkers who leave. But that can be a source of strength, too.

"Our support for each other goes beyond the workplace," said Alexine Chevalier with Priority One Services, which handles human resources for the program's contract staff. "There is a dedication from management and families that makes the program very close-knit." **R**



Magazine cover story featured employees in NIH program.



Wachter chats with lecture attendees at a reception after his talk.

PHOTOS: ERNIE BRANSON

## Wachter

CONTINUED FROM PAGE 1

of hospital medicine at the University of California, San Francisco, is decidedly not a Luddite. He blogs, tweets and lauds the potential for technology to improve patient care. In fact, “I would not today go to a hospital that didn’t have a good computer system,” said Wachter, also professor and interim chair of UCSF’s department of medicine. “There’s no question in my mind that our [world] is safer than before we computerized. But there are unanticipated consequences.”

When a computer error nearly killed a child at UCSF, Wachter decided to explore the pitfalls and promise of health care IT, as described in his recent book *The Digital Doctor: Hope, Hype, and Harm at the Dawn of Medicine’s Computer Age*. There was not an empty chair in Lipsett Amphitheater during his recent CC Great Teachers Grand Rounds.

### A Terrifying Mistake

Health care IT should help prevent human error. But 2 years ago, Wachter recounted, a 16-year-old boy at UCSF Medical Center nearly died when he received a massive overdose of a common antibiotic. A doctor had typed in an order for one 160-mg pill. But after a pharmacist called for a clarification, the doctor went back into the computer to confirm the order, one of the system’s built-in safety measures. But she didn’t realize the order screen had defaulted to milligrams per kilogram, based on the child’s weight in kg. So she keyed in “160”—thinking she was ordering 160 mg, but she actually was ordering 160 mg/kg. The impact? An order for 39 pills.

The state-of-the-art IT system did send

out overdose warnings, but the doctor and pharmacist both missed them. How? Because all of the clinicians—doctors, nurses and pharmacists—have grown immune to all the alerts, particularly since so many are false alarms. In 1 month in the ICUs at UCSF, the monitors threw off more than 2.5 million alerts, most inconsequential.

Stunned by these reports of alert fatigue, Wachter visited Boeing to ask airplane engineers about cockpit alerts.

He learned they spend thousands of hours in simulated flight testing with pilots before releasing the planes for commercial use. During testing, they remove unnecessary alerts so pilots pay attention to every alert, which could mean the difference between life and death.

The nurse who administered the 39-fold overdose thought the amount seemed unusual but figured it must be correct. After all, the doctor and pharmacist cleared the order. And when she scanned the first pill in her barcode scanner, it signaled to her that the correct dose was 39 pills, further convincing her that the order was right. The teenager took each and every pill, then had a massive seizure and stopped breathing. Incredibly, he survived.

### Is There a Doctor in the House?

In 2008, Congress appropriated \$30 billion toward computerizing health care. If done right, electronic health records and other health IT advances have the potential to deliver high-value care, said Wachter. But going electronic has left many doctors’ offices and hospitals unprepared to cope with changes in work flow and patient care.

“In just the last 5 years, American health care has gone from an industry whose information backbone was the Post-it note, the clipboard and the 3-ring binder, to an industry whose backbone is electronic,” said Wachter.

He recounted going on rounds as a medical student, learning a great deal from discussing films with the radiologist in the chest reading room. Radiology went digital a decade before the rest of health care, Wachter said, because digital films became more cost-effective. But then, these

radiology rounds ended. Anyone could see the images anywhere, so they were no longer forced to “go to radiology” to see the only copy of the film.

“I think radiology is a canary in a coal mine,” said Wachter. “It demonstrates the impact of digitization in ways that are often unanticipated and don’t have as much to do with the technology as [with] the people and the work.”

That lost human connection also resonates in patient care, said Wachter. Doctors once lived in their wards, visiting patients, jotting notes in patient charts. Now, he said, hospital hallways look barren; the doctors are all in their quiet rooms, doing their computer work.

### Fixing Health Care IT

Much as Boeing engineers observe and interact with pilots when designing cockpit systems, health care IT sorely needs a similar user-centered model. Wachter urges computer vendors to connect with doctors, nurses, pharmacists and patients as they design software to help maximize patient safety. Improving health care IT, he added, will take two keys, like a safe-deposit box. One is better technology. The second, arguably the more important, is to reimagine the work, with technology serving as a tool.

“One of the big things we got wrong here was treating health IT as a technical problem,” said Wachter. “It is a massive adaptive problem...Understanding its impact on jobs and work flow and culture is fundamental to getting this right.”

Wachter, who previously served on Google’s health care advisory board, said Google and other tech companies are transforming health care into an increasingly wired system. Expect the FitBits and Apple watches of the world to soon connect to electronic health records, he said. Expect new apps that will help patients take care of themselves. And as IT generates more and more patient data, he said, researchers will gain a greater understanding of many diseases.

If done properly, Wachter said, such “consumer-facing IT” could be just a few years away. With improvements in current systems and careful planning, health care IT can truly enhance, rather than encumber, the doctor-patient experience. **R**





Study participant receives a scan in the CC's new photon-counting CT scanner.

PHOTO: CLINICAL CENTER

## Photon-Counting CT Scanner Used in Patients for the First Time

The Clinical Center is investigating the potential use of a new generation of a computerized tomography (CT) scanner, called a photon-counting detector CT scanner, in a clinical setting. The prototype technology is expected to replicate the image quality of conventional CT scanning, but may also provide health care specialists with an enhanced look inside the body through multi-energy imaging. Patients could receive a minimum amount of radiation, while the maximal amount of information needed would be delivered to health care providers.

Over the next 5 years, Dr. David Bluemke, chief of the CC department of radiology and imaging sciences, and his team will continue to develop scan protocols and image-processing algorithms, which could improve screening, imaging and treatment planning for health conditions such as cancer and cardiovascular disease.

"The NIH Clinical Center has helped shape and share research advances and health care for decades," said Bluemke. "Now is an exciting time for us and for our study participants here in the Clinical Center as we help test and develop this CT technology so that it may one day help patients around the world and impact the health care they receive."

## Diabetes Drug May Prevent Recurring Strokes

Pioglitazone, a drug used for type 2 diabetes, may prevent recurrent stroke and heart attacks in people with insulin resistance but without diabetes. The results of the Insulin Resistance Intervention after Stroke (IRIS) trial, published in the *New England Journal of Medicine*, suggest a potential new method to prevent stroke and heart attack in high-risk patients who have already had one stroke or transient ischemic attack. This large, international study was supported by NINDS.

The IRIS trial is the first study to provide evidence that a drug targeting cell metabolism may prevent secondary strokes and heart attacks even before diabetes develops. Insulin regulates metabolism and keeps blood sugar levels from getting too high, along with many other processes, in the body. Insulin resistance is a condition in which the body produces insulin but does not use it effectively.

"This study represents a novel approach to prevent recurrent vascular events by reversing a specific metabolic abnormality thought to increase the risk for future heart attack or stroke,"

said NINDS director Dr. Walter Koroshetz.

"The IRIS trial supports the value of more research to test the vascular benefits of other interventions such as exercise, diet and medications that have similar effects on metabolism as pioglitazone," said lead author of the study Dr. Walter Kernan of Yale University School of Medicine.

## Researchers Find Link Between Death of Tumor-Support Cells, Cancer Metastasis

Researchers have discovered that eliminating cells thought to aid tumor growth did not slow or halt the growth of cancer tumors. In fact, when the cancer-associated fibroblasts (CAFs) were eliminated after 10 days, the risk of metastasis of the primary tumor to the lungs and bones of mice increased dramatically. Scientists used bioengineered CAFs equipped with genes that caused those cells to self-destruct at defined moments in tumor progression. The study, published in *Scientific Reports* Feb. 19, was conducted by Massachusetts General Hospital researchers funded by NIBIB.

What causes cancer to grow and metastasize is not well understood by scientists. CAFs are thought to be fibroblast cells native to the body that cancer cells hijack and use to sustain their growth. However, because fibroblasts are found throughout the human body, it can be difficult to follow and study cancer effects on these cells.

"This work underscores two important things in solving the puzzle that is cancer," said Dr. Rosemarie Hunziker, program director for tissue engineering at NIBIB. "First, we are dealing with a complex disease with so many dimensions that we are really only just beginning to describe it. Second, this approach shows the power of cell engineering—manipulating a key cell in the cancer environment has led to a significant new understanding of how cancer grows and how it might be controlled in the future."

## Vaginal Ring Provides Partial Protection from HIV

A ring that continuously and safely releases an experimental antiretroviral drug in the vagina provided a modest level of protection against HIV infection in women, a large clinical trial in four sub-Saharan African countries has found. The ring reduced the risk of HIV infection by 27 percent in the study population overall and by 61 percent among women ages 25 years and older, who used the ring most consistently.

These results were announced Feb. 22 and simultaneously published online in the *New England Journal of Medicine*.

"Women need a discreet, long-acting form of HIV prevention that they control and want to use," said Dr. Anthony Fauci, director of NIAID, which is the primary funder of the trial. "This study found that a vaginal ring containing a sustained-release antiretroviral drug confers partial protection against HIV among women in sub-Saharan Africa. Further research is needed to understand the age-related disparities in the observed level of protection."

## Eylea Outperforms Avastin for Diabetic Macular Edema with Moderate or Worse Vision Loss

A 2-year clinical trial that compared three drugs for diabetic macular edema (DME) found that gains in vision were greater for participants receiving the drug Eylea (aflibercept) than for those receiving Avastin (bevacizumab), but only among participants starting treatment with 20/50 or worse vision. Gains after 2 years were about the same for Eylea and Lucentis (ranibizumab), contrary to year-1 results from the study, which showed Eylea with a clear advantage. The three drugs yielded similar gains in vision for patients with 20/32 or 20/40 vision at the start of treatment. The clinical trial was conducted by the Diabetic Retinopathy Clinical Research Network, which is funded by NEI.

"This rigorous trial confirms that Eylea, Avastin and Lucentis are all effective treatments for diabetic macular edema," said NEI director Dr. Paul Sieving. "Eye care providers and patients can have confidence in all three drugs."

Eylea, Avastin and Lucentis are all widely used to treat DME, a consequence of diabetes that can cause blurring of central vision due to the leakage of fluid from abnormal blood vessels in the retina. The macula is the area of the retina used when looking straight ahead. The drugs are injected into the eye and work by inhibiting vascular endothelial growth factor, a substance that can promote abnormal blood vessel growth and leakage.

Although the drugs have a similar mode of action, they differ significantly in cost. Study results were published online Feb. 29 in *Ophthalmology*.



On hand at the recent Marfan briefing were (from l) Gavin Lindberg, NIAMS director Dr. Stephen Katz, Isaiah Austin, Dr. Kathleen Mimmagh (Marfan Foundation board of directors) and NHLBI director Dr. Gary Gibbons.

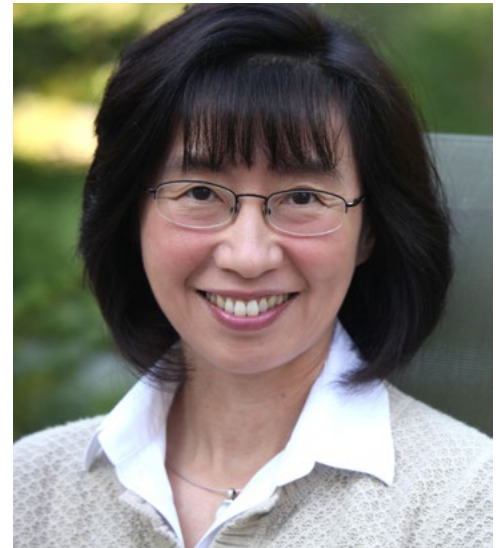
## NIAMS, NHLBI Directors in Briefing with Marfan Advocates

NIAMS director Dr. Stephen Katz and NHLBI director Dr. Gary Gibbons recently joined former Baylor basketball standout Isaiah Austin and others at a congressional briefing about Marfan syndrome.

Marfan syndrome is a heritable connective tissue disorder. Connective tissues hold the body together and provide a framework for growth. In Marfan, the connective tissue is defective, leading to changes in many body systems, including the skeleton, eyes, heart and blood vessels, nervous system, skin and lungs. The briefing, sponsored by the Marfan Foundation, highlighted research opportunities in Marfan and related disorders and advances that will lead to improved patient care.

Reps. Bill Flores (R-FL), Steve Israel (D-NY) and Chris Van Hollen (D-MD) all provided brief remarks to the audience of patients, advocates and congressional staff. They expressed support for continued investment in biomedical research and the critical role of NIH.

Katz and Gibbons discussed recent research advances and highlighted the importance of engagement with the community to enhance and facilitate future research. In addition, Austin and 14-year-old Owen Gray, who both were diagnosed in 2014, spoke about how Marfan has affected their lives. Michael Weamer, president and CEO of the Marfan Foundation, also spoke about his involvement with the foundation. Gavin Lindberg, a former member of the Marfan Foundation board of directors, moderated the session. [R](#)



NIDA grantee Dr. Jeannie Lee has been named the 2016 winner of the Lurie Prize in Biomedical Sciences.

## Grantee Lee Wins 2016 FNIH Lurie Prize

Dr. Jeannie T. Lee, a NIDA grantee, has been named the 2016 winner of the Lurie Prize in Biomedical Sciences for uncovering the functions of long, noncoding RNA in epigenetic regulation. Her work has accelerated the understanding of mechanisms driving epigenetic regulation, which involves changes in gene function without changing the DNA sequence.

Lee's work investigates how a whole sex chromosome can be shut down and how "X-chromosome inactivation" can be leveraged to treat congenital diseases such as Rett, CDKL5 and Fragile X syndromes in addition to numerous cancers such as breast, ovarian, blood, intestinal and male germ cell tumors where there is often an extra x-chromosomal copy.

The Lurie Prize, administered by the Foundation for the National Institutes of Health, will be presented on May 18 in Washington, D.C.

Lee is a professor of genetics and pathology at Harvard Medical School and at Massachusetts General Hospital, as well as a Howard Hughes Medical Institute investigator.

## Your Science on Page 1

The new design of the *NIH Record* relies on high-resolution color scientific images for the masthead on p. 1. We're always on the lookout for more fresh images for future issues of the *Record*. If your research lends itself to high-resolution, print-quality images, consider sharing them with our readership. Email candidate jpgs to the editors, along with a brief caption and credit line. The best images for publication are horizontal, with lots of color and contrast.







Claire Callahan died Feb. 11 in Danvers, Mass.

## NIAAA Alumnus Callahan Mourned

Claire M. Callahan died on Feb. 11 in Danvers, Mass., after a lengthy illness. Her career was devoted to the service of people, principally as an educator of youth, and in the prevention and treatment of addiction.

She held a master's degree in counseling psychology from the University of Texas, with additional doctoral study at Fordham University.

In the early 1970s, Callahan worked with young adults addicted to drugs in Atlanta. She was also a staff psychologist at

the Georgia Regional Hospital of Atlanta, a facility for mentally ill and developmentally disabled patients.

When she and her husband later moved to Washington, D.C., Callahan continued her work at the National Institute on Alcohol Abuse and Alcoholism. There, in a collaborative program between NIAAA and the National Institute on Drug Abuse, she oversaw the development of curricula to educate primary care physicians, nurses, psychologists, social workers and other health care professionals to prevent and treat addiction.

Many of the physicians trained under the NIAAA/NIDA programs were instrumental in forming the Association for Medical Education and Research in Substance Abuse, the American Society of Addiction Medicine and the American Board of Addiction Medicine.

Later in her career, Callahan joined the National Council on Alcoholism of Ireland, directing the first national training program in that country to educate health professionals to develop hospital and community-based programs for prevention, intervention and treatment of alcoholism and other drug addictions.

Callahan is survived by her husband, James, who worked at the National Cancer Institute, and her brother, John Lyons, of Danvers, Mass.



Dr. Jeffrey Cohen, chief of NIAID's Laboratory of Infectious Diseases, greets Dr. Mary K. Estes of Baylor College of Medicine, who gave the 2016 Chanock lecture recently.

PHOTOS: DANIEL SOÑE

## Estes Speaks at Chanock Lecture

Getting an infection in your gastrointestinal tract can be a painful ordeal. Dr. Mary K. Estes, Cullen endowed chair of human and molecular virology at Baylor College of Medicine, discussed noroviruses at the NIAID Chanock Memorial Lecture on Feb. 23 in Bldg. 50.

She and her lab have developed new diagnostics and a promising virus-like particle vaccine for noroviruses—research that may help settle many people's stomachs. [R](#)

## Asthma Research Volunteers

Individuals 18 years or older with asthma are sought to participate in a 1- to 2-day research study in the Cardiovascular and Pulmonary Branch at the National Institutes of Health. A thorough medical evaluation and monetary compensation will be provided. If interested, call (301) 402-1553.

## Study Seeks Healthy Older Adults

Healthy older adults ages 55-75 are invited to participate in an outpatient research study investigating the benefits of omega-3 oil and blackcurrant supplements on vascular health. The goal of the study is to determine whether the supplements improve blood flow and blood vessel function that can affect your heart. Eligible participants must be medication-free and in good general health. The study will be carried out in an outpatient clinic and includes 4 visits over 6 months. Compensation is provided. For more information, call 1-800-411-1222 (TTY 1-866-411-1010) and refer to study 14-NR-0034.

## Liver Disease Patients Needed

An NIDDK research team seeks people with fatty liver disease to participate in a study. Researchers are looking at a breath test to measure how the body breaks down food in people with fatty liver disease. If you have been diagnosed with non-alcoholic fatty liver disease or steatohepatitis, you may be interested in participating. Compensation is provided. For more information, call 1-866-444-2214 (TTY 1-866-411-1010) and refer to study 15-DK-0080.

## Volunteers Needed for Energy Study

NIDDK seeks healthy Caucasian men, 55-75 years old, and women 18-35 to participate in a research study. Doctors want to learn how the body burns energy at different temperatures. You will have an 8-day inpatient stay at the Clinical Center. Compensation is provided. For more information, contact the Office of Patient Recruitment, 1-866-444-2214 (TTY 1-866-411-1010). Refer to study 12-DK-0097.

## NHGRI Seeks Volunteers

NHGRI researchers seek people with chromosome abnormalities involving the sex chromosomes for a research study. Compensation is provided. For more information, call 1-866-444-2214 (TTY 1-866-411-1010) and refer to study 12-HG-0181.

## IWS AND TES

## Construction Begins on Water, Thermal Storage Systems

Construction began on Mar. 1 for an industrial water storage system and a thermal energy storage system—both on the south side of campus—that will greatly increase the efficiency and reliability of the NIH Central Utility Plant (CUP). The projects are intended to ensure that NIH research and patient care can continue uninterrupted if there is an unexpected power outage or disruption in public utility services.

Large research campuses such as NIH require a reliable chilled water supply to control building temperature and humidity to rigorous specifications and to operate critical equipment. Without this ability, many NIH functions would have to be curtailed. Currently, the Washington Suburban Sanitary Commission supplies water to NIH.

In December 2008, a 66-inch water main broke beneath the 8500 block of River Rd. in Carderock. This caused NIH to experience low water pressure. The event prompted the Office of Research Facilities to commission a study of NIH's water needs in case of possible future disruptions. The study recommended that NIH expand its water storage capacity to ensure the availability of chilled water at all times. The two new systems, under the supervision of ORF's Gias Ahmad, will serve this purpose.

The industrial water storage (IWS) system includes a 5-million-gallon water tank at parking lot 41 and will supplement the existing 5,000-ton chillers and cooling towers in the CUP. The tank, 65 feet high and 120 feet in diameter, will increase water capacity and provide a backup for chilled feed water to offset evaporation and also provide boiler feed water. This will allow NIH to meet the need for water for a few days if a water supply interruption occurs, ensuring reliable cooling and heating to campus buildings.

During construction of the IWS system, part of lot 41 will close, resulting in the loss of roughly 300 parking spaces. To minimize disruption, stacked parking will resume in MLP-8. The Natcher Bldg. garage and MLP-7 are nearby parking alternatives for those who use lot 41. A new surface parking lot will be built near the tank, which will partially offset the spaces affected by the IWS tank.

Construction is also under way for a second, larger water facility, the thermal energy storage (TES) system, on the Bldg. 34 site. It will hold 8 million gallons of chilled water and stand 100 feet high, with the same diameter as the IWS tank. Bldg. 34, the old campus utility plant, will be demolished. Construction on both the IWS and TES systems is expected to be complete by October 2017.

Thermal storage is a low-cost, highly efficient form of energy storage. Combined with other energy sources, thermal storage provides a "green" tool



Renderings of two new cylindrical water tanks that will serve the small town that is NIH's Bethesda campus. Above, the southeast view. Below, a look from the west.



that can help in achieving LEED certification for the building or facility owner. Off-peak energy consumption (power used during the night) can be utilized to meet on-peak demand (power used during the day) by producing an energy source locally at night when it is more efficient and cheaper to generate and using it during peak demand times. Utility companies charge more for on-peak power consumption than for off-peak power consumption and also charge for peak power use. Thus, thermal storage helps reduce peak power demand.

Other advantages of thermal storage include:

- ◆ Reduced utility-bill peak demand resulting in decreased electrical costs

- ◆ Reduced strain on the power grid—using nighttime energy balances the distribution of energy needs 24 hours a day so there isn't as much peak demand during the daytime

- ◆ Reduced energy consumption

NIH's cooling load is one of NIH's largest single utility costs. When combined with buildings' energy use, the time of peak cooling energy needs produces the highest electrical demand. That peak electrical demand is not only costly to NIH, but also creates challenges for the electric utility serving campus. Adding chilled water thermal storage can make existing chillers serve a far greater load than the installed equipment capacity.